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Patient's perspective on epilepsy: self-knowledge among Omanis

SAMIR AL-ADAWI[†], HAMOUD AL-SALMY[‡], ROGER G. MARTIN[†], AZIZ AL-NAAMANI[†], SUBHASHINI PRABHAKAR[§], DIRK DELEU[‡], SAMIRA MOOSA[¶] & ATSU S.S. DORVLO[‖]

Departments of [†]Behavioural Medicine and Psychiatry and [‡]Clinical Pharmacology and Therapeutics, College of Medicine, Sultan Qaboos University, Muscat, Oman; [§]Department of Neurology, Royal Hospital, Muscat, Oman; [¶]Education Research Center, College of Education, Sultan Qaboos

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Correspondence to: Dr Atsu S. S. Dorvlo, Department of Mathematics and Statistics, Sultan Qaboos University, P.O. Box 36, Al-Khoudh 123, Muscat, Sultanate of Oman. *E-mail*: atsu@squ.edu.om

Improving patients' knowledge has been suggested to improve their symptoms and prognosis. Very little is known about epileptic patient's knowledge of their illness in cross-cultural settings. This pilot study investigated what Omani patients know about their disorder. Patients attending a tertiary hospital completed a structured knowledge questionnaire to elicit information pertaining to aetiology, safety, compliance with medication regimes, legal and employment issues concerning epilepsy.

Although correctly endorsing issues related to their medication, this cross-cultural sample was found to have limited knowledge about their condition. In particular, most patients were unable to give accurate indications of epilepsy, neither were they able to give correct responses to questions pertaining to safety and compliance. There is a need for improving patient's knowledge. As with other chronic disorders, people with epilepsy in Oman should receive systematic health education about how to manage the condition most effectively.

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INTRODUCTION

Epilepsy is one of the world's most prevalent non-communicable diseases[1] affecting approximately 25 million people in the world[2]. In non-western societies, epilepsy is still the prerogative of the traditional healers[3]. With the spread of biomedical care, people with epilepsy (PWE) are increasingly seeking 'western type treatments'[4]. Although the triumph of modern drugs over 'falling sick' has improved the quality of life[5,6], little is known about how PWE understand their condition particularly in those societies where epilepsy appears to be 'culturally devalued'[7] and often equated with either sacredness or demonic possession[6].

In terms of awareness and social acceptance, numerous surveys carried out on general populations in different parts of the non-industrialised world suggest PWE are often viewed with attitudes that become breeding ground for myths, stigma and exclusion[8]. More disheartening, however, is the evidence suggesting that, on average, even medical practitioners in developing countries still harbour negative attitudes toward PWE[9]. The best antidote to these negative attitudes is to ensure that patients understand exactly what epilepsy is. Without such knowledge, PWE are likely to become the victims of other's misconceptions.

Previous studies suggest that there is a direct relationship between patients' understanding of their disability and their evolving proper coping mechanisms[5]. It has long been known that 'each patient carries his own doctor inside him'[10]. By enabling this 'doctor' to work, a PWE can achieve a great degree of control over his or her seizures, making it possible for a greater self-management of the seizures. The PWE may be more aware of their own needs and of the services available to meet those needs[11]. The self-advocacy skills of the PWE may also improve, which puts them

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in a better position to explain their condition to others and thereby promote a positive view of epilepsy[10].

In developing countries, few investigations have been conducted to explore PWE's self-knowledge of their condition. In the West, several studies have reported that PWE knew only a little more, and in some cases even less, about their disorder than those without epilepsy[5,12–17]. Long *et al*.[18] have evaluated what PWE know about their disorder in terms of safety, compliance and legal issues concerning driving and employment. While it has been widely established that improving patient knowledge may improve symptom control, Long *et al*.[18] revealed that, irrespective of demographic parameters such as age, education and duration of the illness, PWE tend to have limited knowledge about their condition. As a result, PWE are not likely to come to terms with their condition. In developing countries, although a few studies have examined cultural attitudes and awareness of epilepsy[7,19–22], to our knowledge no studies have been undertaken in the Arab world. As the incidence and prevalence of epilepsy are thought to be several-fold higher in developing than in industrialised countries[2], there is clearly a pressing need for examining how much patients from developing countries with epilepsy understand about their disease.

Oman offers an interesting study area since comprehensive health services have only recently been introduced. Its diverse society has experienced minimum acculturation and many of its customs (e.g. consanguinity) and geographical features (mountains) may exacerbate the incidence of epilepsy. Studies conducted elsewhere have suggested that there is a greater prevalence of seizure in rural and mountainous terrains than in other areas among similar age groups[8]. Similarly, widely prevailing cultural practices of consanguinity[23], and high road traffic accidents[21], injuries and non-communicable diseases are likely to increase the number of PWE in Oman[24]. Pertinent to this, physical health and living standard, as a result of the exploitation of oil, have dramatically improved in the past decades. Such trends, compounded with a high birth rate, would inevitably result in more people living longer. This may mean that the absolute number of people afflicted with chronic conditions, including epilepsy, is likely to be greater.

Previous studies have suggested that both education and socio-cultural factors tend to influence one's identity, and, by implication, one's self-knowledge. It is not clear how education influences self-knowledge in a country that has only been recently introduced to modern education. In industrialised countries, during the normal course of development, an individual goes through an important psychosocial separation from those who reared and nurtured him or her. Inherent in this separation is the formation of a unique, autonomous identity[25]. However, no parallel individual development occurred in Arab or Omani society. Instead, collective identity of the family and tribal affiliation appear to be central in individual identity. From such a background, there is a dearth of research on how an individual, in this case, afflicted with chronic illness, regards his or her condition. As illness behaviour is often dictated by an individual's socio-cultural identity[7], little is known of how PWE from an Arab/Muslim country like Oman conceive their condition. A principal aim of this study is to examine the extent of an epileptic patient's knowledge about his/her condition in the Omani cross-cultural setting. This study would help to audit the result of the decade of the *Global Campaign Against Epilepsy*[1,26].

METHOD

The questionnaire, an *Epilepsy Patient Knowledge Questionnaire* (EPKQ), was adapted from Long *et al*.[18] and modified for brevity and to accommodate some socio-cultural aspects of Oman. EPKQ has been found to yield important information on what PWE know about their disorder. Such information could be clinically useful and theoretically relevant to plan health education, to monitor the adjustment of PWE to their condition, as well as to indicate what provisions are needed to sustain adequate intervention and management of PWE.

The adopted EPKQ contained demographic information, number of years with epilepsy and education level. The EPKQ consists of multiple choice and true or false type questions that elicit information on concept of epilepsy and management, medication compliance, social activities and some legal issues.

The EPKQ was translated by experienced staff members into Arabic, using a method of back-translation as suggested by Chaplin and Malmgren[27] in order to make the modified EPKQ dialectically adaptive to an Omani sample. This protracted exercise has been shown to ensure conceptual, semantic, and technical equivalency between the source measures and the target measures[9]. During preparation of the study, interviewers were trained to reliably read out the items of the EPKQ in the local dialect of spoken Arabic, and to rate the responses accordingly. As a result, there was substantial inter-rater agreement of the various items of the questionnaire.

The study constituted a 'natural observation' of patients attending a tertiary care hospital in Muscat, the capital of Oman. Once oral consent was taken from the patients, and were assured that the data would be confidential, they were given a brief explanation of the study. As illiteracy was rife among the PWE[8,28], for brevity and consistency, all the items of the EPKQ

were read to all the patients. Those patients with known sensory or cognitive impairment that would affect proper completion of the questionnaire were excluded from the sample. The study was approved by both 'Ethic Committee for Human and Clinical Research' and 'Medical Research Committee' (Project No. MED 99-4) of College of Medicine, Sultan Qaboos University.

RESULTS

There was 107 patients of which 53% ($n = 57$) were males and the other 47% ($n = 50$) were females. The age of the patients range from 17 to 44 years (mean = 22.64 ± 4.55), with 56% ($n = 60$) in the age range from 17 to 23. The mean number of years that patients had epilepsy was 6.55 ± 5.95. Fifty-eight percent ($n = 62$) of the patients started having seizures within 5 years before the survey. The average number of years that this group of patients has been receiving treatment from a hospital was 5.50 ± 5.84.

There were 20 (18.7%) patients who were illiterate or had a cursory knowledge of the Koran. Nine patients had only primary school education, 59 had secondary education and only five had university education.

Table 1 showed the number of patients who gave correct responses to each of the questions on the questionnaire. It is clear that over all the majority of patients gave the wrong response to most of the questions ($P < 0.001$). The notable exception was that all the patients agreed that hospital medication appears to be most effective in treating epilepsy. Figs. 1–6 show the number of patients giving specific responses.

EPILEPSY AND TREATMENT

The majority of the patients (70/107) think that supernatural causes or spirits cause epilepsy. Sixty-three percent of those with little or no education think that it is caused by supernatural causes, while 79% of those with some education also believe that spirits and supernatural forces cause it. Fourteen patients with no education knew that epilepsy is caused by a scar in the brain or by abnormal electrical discharge while none of the educated patients knew this. Despite these views, all participants endorsed the view that seizures can be treated with biomedical interventions. On the other hand, none of the patients suggested the suitability of traditional medicine or other socio-cultural interventions in the management of epilepsy. Therefore, although barely 13% knew the causes of epilepsy, the entire group acknowledged the importance of modern drug treatment in the management of their condition.

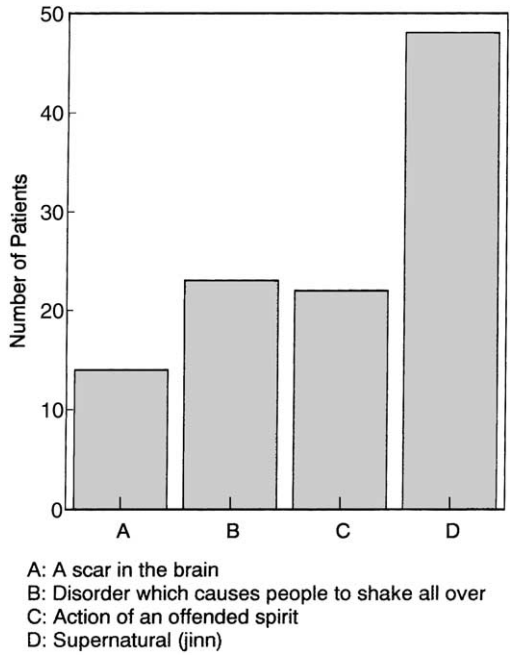

Fig. 1: What is epilepsy.

Table 1: Distribution of correct responses to the questions on knowledge.

	Correct response	Incorrect response	Total
What is epilepsy?	14	93	107
Can epilepsy be treated with hospital medication?	107	0	107
Knowledge of situations that increase risk of seizure	19	88	107
Should a foreign object be put in mouth during seizure	53	54	107
Continue taking medication during pregnancy	63	44	107
Types of activity that is safe for an epileptic	46	61	107
What to do in case of side effects due to medications	32	75	107
What to do when you stop having seizures	68	39	107
Conditions under which an epileptic can drive	16	91	107
Epileptic can engage in all kinds of jobs	65	42	107
Should employers ask about epileptic background	79	28	107

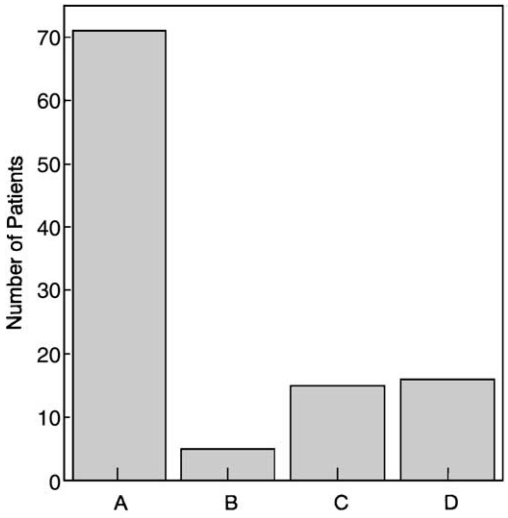

Fig. 2: Conditions under which an epileptic can drive.

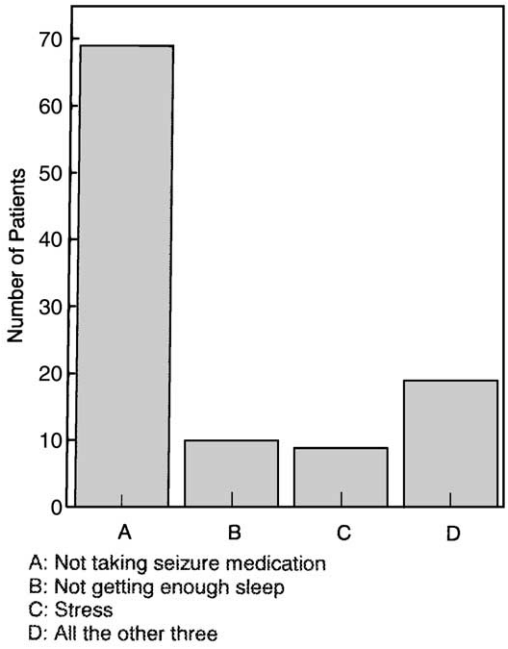

Fig. 3: Knowledge of situations that increase risk of seizure.

LEGALITIES OF DRIVING AND EMPLOYMENT

Although there are no legal provisions concerning epilepsy and driving in Oman, 71 (66.4%) thought that PWE should drive only when someone else is in the car. Fifteen (14%) thought that one can drive but pull over whenever one experiences an aura. Five (4.7%) thought that one may 'double up' anti-convulsant therapy and then drive. Such diverse answers suggest that

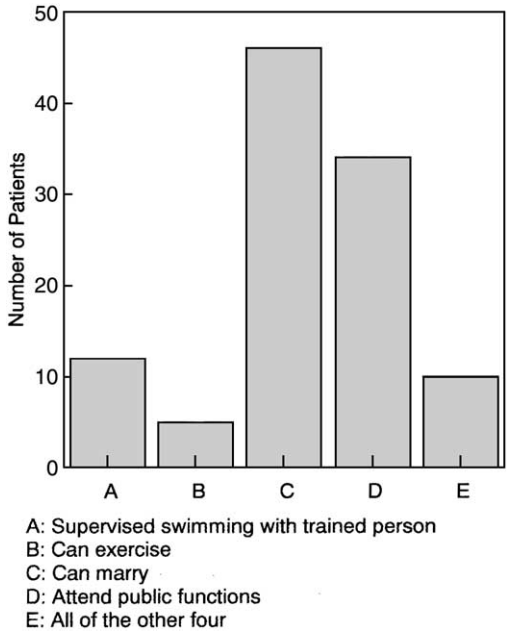

Fig. 4: People with epilepsy may do all the following activities.

only 15% of the patients knew the correct response, namely, none of the above. Finally, 65 (60.7%) agreed with the statement that people with epilepsy can work in many types of jobs and 79 (73.8%) thought that it is illegal for employers to ask if one has epilepsy.

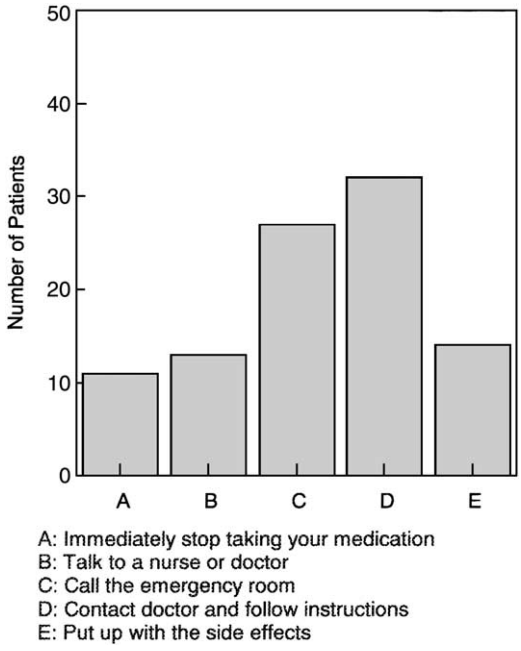

Fig. 5: What to do in case of side effects due to medications.

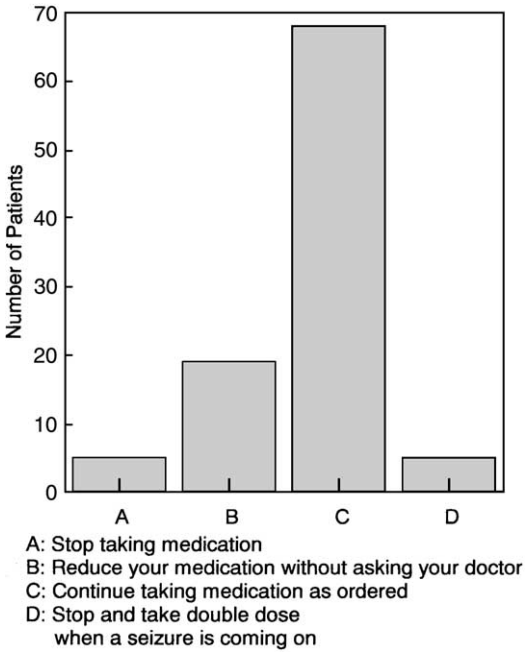

Fig. 6: What to do when you stop having seizures.

SAFETY

In general, the patients knew that some safety precautions need to be taken by epileptic patients. However, only 18% knew that not taking seizure medication, not getting enough sleep and stressful situations increase the chances of seizures. About 50% knew that foreign objects should not be put in the mouth during seizures, while 40% believed that a pregnant woman should not continue to take her epilepsy medication. Less than 43% think that an epileptic can marry, another 32% believe they can attend public functions, while 16% think that they can swim or exercise under supervision. A very low percentage, only 9%, believes that a person with epilepsy can lead a full life and be able to do all these activities.

COMPLIANCE

On the issue relating to adverse drug effects of seizure medications, 32 patients (29.9%) correctly thought one must first contact his or her doctor if side effects occur. Twenty-seven (25.2%) think the PWE must report to the emergency department in a hospital, while 24 (22.4%) think the patient ought to stop taking anti-convulsant therapy upon experiencing side effects due to the medication. Fourteen (13.1%) were stoic, endorsing the view that one must continue to take medication regardless of its adverse effects.

Regarding when one should cease to take medication, 68 (63.6%) suggested that one must continue to take anti-convulsant therapy even if he or she is seizure free. Nineteen (17.8%) thought that one must reduce his or her dosage without asking for the consent of a doctor or nurse. Ten (9.4%) felt either that one should stop or reduce the dosage when he/she was seizure free for sometime.

DISCUSSION

The primary aim of this study was to examine what patients with epilepsy in Oman understand about epilepsy including issues related to treatment, safety, compliance, employment and legal issues. An understanding of epilepsy, both its physical and social implications, has increased in the world health agenda[1]. The catalyst for this has been the decade of the Global Campaign Against Epilepsy—implemented by the International League Against Epilepsy, the International Bureau for Epilepsy and the World Health Organization[26, 29]. The result of such campaigns has shown increased awareness in the general population toward PWE[30, 31]. One conspicuous challenge to this development is emerging evidence showing that PWE themselves appear to know little about epilepsy compared to those without the disease[12]. One possible explanation for this is the lack of education among people with epilepsy. However, this assumption does not hold with the present data as well as those of others[18]; PWE, regardless of their educational attainment, or geographical origin, have limited knowledge of their condition. Although behaviour during illness is often dictated by an individual's socio-cultural identity[32], at face value, the present study suggests that lack of knowledge appears to transcend culture. However, it is not clear whether lack of knowledge is due to inherent part of the illness or a reaction to it.

Although traditional healing rituals are best in offering psychological comfort as well as mending social rifts[14], the prevailing view suggests modern anti-epileptic drugs are more effective in the treatment of seizures. On items pertaining to the aetiology of epilepsy, the majority favored the role of a sensate agent as the aetiological factor of their disorder. Appearing to contradict themselves, the majority held the view that epilepsy can only be treated with biomedical drugs. Again, despite supernatural attribution and the prevailing view that in developing countries epilepsy is the prerogative of the traditional healers[6], none of the patients acknowledged the efficacy of cultural and religious interventions. Were our respondents, therefore, more subjective than factual, perhaps 'trying to put their best foot forward' in the light of subtle demand

characteristics such as being under biomedical care? Although this possibility remains, therapeutically the effectiveness of anti-epileptic drugs to control their seizures might have created such knowledge, attitude and perception. This realization may be because all the patients were receiving treatment in a tertiary care hospital and may have been influenced by some improvement in their condition. Therefore, although in developing countries PWE tend first to seek help from traditional healers[6], possible previous failure of traditional intervention may have contributed to such conflicting views in our sample. Consistent with this view, the majority correctly thought that women with epilepsy should not stop taking their medication even if they are pregnant. Alternatively, as the concept of epilepsy in traditional communities is often equated with a wide range of explanations[2], some biomedical views of epilepsy might be congruent with traditional belief[33].

The present sample invariably showed a lack of knowledge of safety and compliance topics. For example, although current understanding suggests that an object placed in the mouth is liable to damage the oral mucosa as well as interfere with inhalation[18]; the majority erroneously thought that it is appropriate to place an object in a patient's mouth during a seizure to prevent further injuries. Similarly, 41.9% mistakenly judged that pregnant women with epilepsy should cease taking anti-epileptic drugs. This, of course, contradicted what has often been recommended; despite potential complications for both foetus and mother, approximately 0.5% of all pregnancies occur in women with epilepsy, and 95% of infants born to these women are normal and healthy[34, 35]. Only 10% responded accurately to the notion that PWE can swim and exercise under supervision, participate in social activities and even get married. The majority of the patients did not know what to do in case of the onset of side effects due to the anti-epileptic drugs. Although one has to be seizure free for 2–3 years before attempting to discontinue medication, a substantial number of our patients gave a wrong response in this regard. Finally, as there are no regulations on the welfare of PWE in Oman, it is not surprising, therefore, that the majority of the sample did not give correct responses on the issues pertaining to legality of driving and employment.

Some limitations of this study should be highlighted. Data collection by questionnaire is not without problems. Although some structured questionnaires are easy to apply, studies have found that different cultures attach different meanings to life and thus conceive reality differently[36]. Although all the items of the screening instrument were translated to achieve conceptual equivalence in the Omani dialect, its usefulness could still be hampered by certain subtle linguistic and conceptual misunderstandings that might not have been apparent during translation and piloting[27]. Al-Adawi[37] has suggested that causal attributions tend to differ from culture to culture. In attitudinal studies on cross-cultural samples, qualitative interviews are likely to be more fruitful. On the other hand, had the present Omani patients scored differently because of cultural differences, then the present findings would have been seemingly different from those of others[5, 17, 18]. As this was not the case, at face value, self-knowledge elicited by the present subjects can be considered genuine. Secondly, although attitude determines for each individual what he will see and hear, what he will think and what he will do, the question remains whether this attitude and behaviour would generalise into a 'real' situation. Thirdly, the population of the present study was derived from those seeking care at a tertiary medical centre, thus the generalisation of this study could be limited by possible ascertainment bias. Fourthly, epilepsy in developing countries is more likely to go unreported than in developed countries. Many cases that never reach medical attention may be construed as spirit possession, or simply hidden to avoid social stigmas[6]. However, with the introduction of 'western treatment' and having exhausted what is often thought of as ineffective treatments from traditional healers, PWE, in the words of Watts[4], 'were prepared to travel long distances' (p. 465) to get treatment from health centres. This study can be criticised on the grounds that it did not use the more commonly used assessment measures such as Epilepsy Knowledge Questionnaire[38, 39] (EKQ). However, the questionnaire used EPKQ[18] is relatively simple, easy to administer and contains only 11 items for cross-cultural subjects who are mostly illiterate. More recently, it was found to have adequate lexical comparability and conceptual equivalence in other cross-cultural populations[22]. The present questionnaire was specifically designed to elicit information on knowledge among PWE towards their condition rather than gauge psychosocial functioning as in other assessment tools[38]. Finally, this study was naturalistic and descriptive. Therefore, it would be necessary to replicate it within a larger sample using experimental designs that will control for some conditions. In order to preserve the naturalistic properties of the observation, this study relied entirely on subjective reports. Detailed information was not collected on seizure, except information necessary to admit the patient into the study, and not on medication. These could form the basis of further study.

Despite this caveat, the present study suggests that PWE in Oman have limited knowledge about their condition, a finding similar to other studies carried out in developed countries. Lack of knowledge toward

their condition among PWE appears to be an inherent part of their illness that does not depend on culture or other demographic factors. In this climate, it is not surprising, therefore, that, in developing countries, around 90% of PWE are not receiving appropriate treatment[1,32]. Consequently, PWE continue to be stigmatised and have a more distressing quality of life than people with other non-communicable illnesses[26]. As a heavily stigmatised disorder, epilepsy is surrounded by a number of common misconceptions that can contribute to poor psychosocial adjustment problems in the medical management of this condition. In order to galvanise more self-knowledge among PWE, education is crucial. Epilepsy is amenable to behavioural intervention. As with other chronic disorders, people with epilepsy should receive systematic health education about how to manage the condition most effectively. As it has already been established, improving patients' knowledge may improve their symptoms and prognosis. Patient education about their illness appears to be a critical factor for quality care and compliance and we would do well to heed the old saying, 'Know thy self'.

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